

2018 Current Fiscal Year Report: National Cancer Institute Council of Research Advocates

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1. Department or Agency

Department of Health and Human Services

2. Fiscal Year

2018

3. Committee or Subcommittee

National Cancer Institute Council of Research Advocates

3b. GSA Committee No.

5248

4. Is this New During Fiscal Year?

No

5. Current Charter

08/17/2018

6. Expected Renewal Date

08/17/2020

7. Expected Term Date

8a. Was Terminated During Fiscal Year?

No

8b. Specific Termination Authority

8c. Actual Term Date

9. Agency Recommendation for Next Fiscal Year

Continue

10a. Legislation Req to Terminate?

Not Applicable

10b. Legislation Pending?

Not Applicable

11. Establishment Authority

Authorized by Law

12. Specific Establishment Authority

42 U.S.C. 285a-2(b)(7)

13. Effective Date

11/20/1985

14. Committee Type

Continuing

14c. Presidential?

No

15. Description of Committee

Scientific Technical Program Advisory Board

16a. Total Number of Reports

No Reports for this Fiscal Year

17a. Open Meetings and Dates 1 17b. Closed Meetings and Dates 0 17c. Partially Closed Meetings and Dates 0 Other Activities 0 17d. Total Meetings and Dates 1

Purpose

Program Advisory and/or Policy

Start

06/21/2018

End

- 06/21/2018

Number of Committee Meetings Listed: 1

	Current FY	Next FY
18a(1). Personnel Pmts to Non-Federal Members	\$2,800.00	\$2,800.00
18a(2). Personnel Pmts to Federal Members	\$0.00	\$0.00
18a(3). Personnel Pmts to Federal Staff	\$48,165.00	\$49,080.00
18a(4). Personnel Pmts to Non-Member Consultants	\$0.00	\$0.00
18b(1). Travel and Per Diem to Non-Federal Members	\$2,564.00	\$2,599.00
18b(2). Travel and Per Diem to Federal Members	\$0.00	\$0.00
18b(3). Travel and Per Diem to Federal Staff	\$0.00	\$0.00
18b(4). Travel and Per Diem to Non-member Consultants	\$0.00	\$0.00
18c. Other(rents,user charges, graphics, printing, mail, etc.)	\$2,292.00	\$2,338.00
18d. Total	\$55,821.00	\$56,817.00

20a. How does the Committee accomplish its purpose?

The role the National Cancer Institute's Council of Research Advocates (NCRA) is to identify and respond to issues and challenges facing the Institute and the cancer research community, at the request of the NCI Director. Board members provide informed, non-scientific perspectives relevant to promoting research outcomes that are in the best interest of patients. This includes identifying new approaches, promoting innovation, recognizing unforeseen risks or barriers, and identifying unintended consequences that could result from NCI or other federal government decisions or actions, as well as enhancing input, optimizing outreach, and promoting strong collaborations, all with respect to non-scientist stakeholders, in the interest of meeting common Institute and community goals. In FY2018, NCRA held one meeting on June 21, 2018 (in-person). Members were provided an update on budget, legislative, and clinical research activities before providing their thoughts, insights, and observations to the NCI Director.

20b. How does the Committee balance its membership?

The Committee consists of up to 16 members, including the Chair appointed by the Director, NCI. The membership consists of cancer research advocates who are involved in the cancer experience and possess an expert understanding of non-scientific burdens to cancer research as well as of the perspectives and dynamics of the research, patient, policy, and advocacy communities interested in cancer research and cancer care delivery. This expert understanding will have been gained through experience working in the cancer consumer advocacy field, affiliation with a cancer related professional society, affiliation with a research foundation involved in cancer research or healthcare, experience as a health care professional focused on the study of cancer and other related diseases, or experience serving as a thought-leader in an area related to cancer research and care delivery.

20c. How frequent and relevant are the Committee Meetings?

Meetings of the full Committee will be held approximately 2-3 times within a fiscal year. The Committee met one time during this reporting period to advise and make recommendations to the Director, NCI, from the perspective and viewpoint of cancer research advocates on a wide variety of issues, programs and research priorities. In FY2018, the NCRA meeting was held on June 21, 2018 (in-person). Due to scheduling difficulties, the NCRA Meeting scheduled to be held on September 17, 2018 was rescheduled to October 19, 2018.

20d. Why can't the advice or information this committee provides be obtained

elsewhere?

The membership consists of cancer research advocates who possess an expert understanding of non-scientific burdens related to cancer research, as well as of the perspectives and dynamics of the research, patient, policy, and advocacy communities interested in cancer research and cancer care delivery. The advice is not available from NCI staff or existing committees.

20e. Why is it necessary to close and/or partially closed committee meetings?

N/A

21. Remarks

Reports: This committee did not produce any public reports. Members: The terms for David Arons, Gregory Aune, Mary Ann Battles, Shelly Fuld Nasso, Martha Gaines, June McKoy, Senaida Poole (Fernandez), and Regina Vidaver have been administratively extended. As such, their term of service end dates are different than what was reported on the FY17 ACR. Meetings: The committee had one meeting in FY18. Costs: The decrease in operating costs for FY18 are due to a decrease in the number of meetings held in FY18. The reduction in Federal Staff costs is due to staffing changes.

Recommendations: The FY18 meeting focused on NCI clinical research initiatives and served to educate NCRA members on these major activities, as well as provide an opportunity for members to interact with the NCI Director. Thus, no recommendations were made in FY18. The DFO and Committee Decision Maker positions are held by the same individual because of the assignment of responsibilities within the Institute.

Designated Federal Officer

AMY WILLIAMS ACTING DIRECTOR, OFFICE OF ADVOCACY RELATIONS

Committee Members	Start	End	Occupation	Member Designation
ARONS, DAVID	10/21/2012	09/30/2018	CHIEF EXECUTIVE OFFICER	Special Government Employee (SGE) Member
AUNE, GREGORY	02/22/2015	09/30/2018	ASSISTANT PROFESSOR OF PEDIATRICS	Special Government Employee (SGE) Member
BANGS, RICHARD	03/04/2018	06/30/2020	RESEARCH ADVOCATE	Special Government Employee (SGE) Member
BATTLES, MARY ANN	11/29/2015	09/30/2018	HEAD, CLINICAL QUALITY & COMPLIANCE	Special Government Employee (SGE) Member
FLESHMAN, JULIE	10/01/2017	06/30/2020	PRESIDENT & CHIEF EXECUTIVE OFFICER	Special Government Employee (SGE) Member
FRIEDMAN, SUE	11/29/2015	06/30/2019	EXECUTIVE DIRECTOR	Special Government Employee (SGE) Member
FULD NASSO, SHELLEY	05/17/2015	09/30/2018	CHIEF EXECUTIVE OFFICER	Special Government Employee (SGE) Member
GAINES, MARTHA	02/21/2014	09/30/2018	DIRECTOR, CENTER FOR PATIENT PARTNERSHIPS	Special Government Employee (SGE) Member
LEACH, DANIELLE	03/04/2018	06/30/2020	DIRECTOR OF ADVOCACY AND GOVERNMENT RELATIONS	Special Government Employee (SGE) Member

MCKOY, JUNE	01/10/2016	09/30/2018	ASSOCIATE PROFESSOR OF MEDICINE	Special Government Employee (SGE) Member
POOLE, SENAIDA (FERNANDEZ)	05/31/2015	09/30/2018	PROGRAM OFFICER	Special Government Employee (SGE) Member
VARGAS, ROBERTO	12/13/2015	06/30/2019	NAVIGATOR, COMMUNITY ENGAGEMENT AND HEALTH POLICY PROGRAM	Special Government Employee (SGE) Member
VIDAVER, REGINA	03/23/2014	09/30/2018	SECTION CHIEF	Special Government Employee (SGE) Member

Number of Committee Members Listed: 13

Narrative Description

The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. The NCI Council of Research Advocates (NCRA), is the only federal advisory committee comprised of advocate leaders at NCI. NCRA members are chosen for their expert knowledge of issues of importance to the cancer research community. The NCRA identifies and responds to issues and challenges facing the Institute and cancer research community and provides advice to the NCI Director around approaches to enhance community input, optimize community outreach, and promote effective collaborations that will help address these challenges and lead to improved research outcomes. In addition, NCRA members bring their unique skills and perspectives by identifying new approaches, promoting innovation, recognizing unforeseen risks or barriers, and identifying unintended consequences that could result from NCI decisions. The NCRA focuses on enhancing community input, optimizing community outreach, and promoting strong collaborations to improve research outcomes.

What are the most significant program outcomes associated with this committee?

Checked if Applies

Improvements to health or safety	<input type="checkbox"/>
Trust in government	<input checked="" type="checkbox"/>
Major policy changes	<input type="checkbox"/>
Advance in scientific research	<input type="checkbox"/>
Effective grant making	<input type="checkbox"/>
Improved service delivery	<input type="checkbox"/>
Increased customer satisfaction	<input checked="" type="checkbox"/>
Implementation of laws or regulatory requirements	<input type="checkbox"/>
Other	<input checked="" type="checkbox"/>

Outcome Comments

Public engagement in the research process.

What are the cost savings associated with this committee?

Checked if Applies

- | | |
|----------------------------|-------------------------------------|
| None | <input type="checkbox"/> |
| Unable to Determine | <input checked="" type="checkbox"/> |
| Under \$100,000 | <input type="checkbox"/> |
| \$100,000 - \$500,000 | <input type="checkbox"/> |
| \$500,001 - \$1,000,000 | <input type="checkbox"/> |
| \$1,000,001 - \$5,000,000 | <input type="checkbox"/> |
| \$5,000,001 - \$10,000,000 | <input type="checkbox"/> |
| Over \$10,000,000 | <input type="checkbox"/> |
| Cost Savings Other | <input type="checkbox"/> |

Cost Savings Comments

NCI supports basic, translational and clinical research which often takes many years to deliver clinically applicable scientific advances.

What is the approximate Number of recommendations produced by this committee for the life of the committee?

93

Number of Recommendations Comments

The NCRA is an advisory committee designed to provide perspective, feedback, and ideas to the NCI. NCRA also provides a forum for government and private groups to work together to address critical issues that affect NCI's work. No recommendations were made in FY18.

What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?

40%

% of Recommendations Fully Implemented Comments

The percentage of recommendations implemented as stated above were developed at the time the Annual Comprehensive Report was prepared.

What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?

40%

% of Recommendations Partially Implemented Comments

The percentage of recommendations implemented as stated above were developed at the time the Annual Comprehensive Report was prepared.

Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?

Yes ☒ No ☐ Not Applicable ☐

Agency Feedback Comments

E-mail updates and presentations at the meetings. NCI leadership gave feedback directly to the NCRA through meetings with the full advisory group. The NCI community is made aware of NCRA activities through NCI's Office of Advocacy Relations.

What other actions has the agency taken as a result of the committee's advice or recommendation?

Checked if Applies

Reorganized Priorities	<input type="checkbox"/>
Reallocated resources	<input type="checkbox"/>
Issued new regulation	<input type="checkbox"/>
Proposed legislation	<input type="checkbox"/>
Approved grants or other payments	<input type="checkbox"/>
Other	<input checked="" type="checkbox"/>

Action Comments

The Committee makes recommendations to federal staff by responding to issues and challenges facing the Institute and cancer research community and provides advice to the NCI Director around approaches to enhance community input, optimize community outreach, and promote effective collaborations that will help address these challenges and lead to improved research outcomes. As a result, specific topics of interest to the cancer research advocacy community are defined and integrated into the NCI's Office of Advocacy Relations communications strategy and plan.

Is the Committee engaged in the review of applications for grants?

No

Grant Review Comments

N/A

How is access provided to the information for the Committee's documentation?

Checked if Applies

Contact DFO	<input checked="" type="checkbox"/>
Online Agency Web Site	<input checked="" type="checkbox"/>
Online Committee Web Site	<input checked="" type="checkbox"/>
Online GSA FACA Web Site	<input checked="" type="checkbox"/>
Publications	<input checked="" type="checkbox"/>
Other	<input checked="" type="checkbox"/>

Access Comments

Information on the NCRA can be found at the NCI Division of Extramural Activities: Advisory Boards, Committees and Review Groups website at <http://deainfo.nci.nih.gov/advisory/ncra/ncra.htm>. Each NCI committee's charter, minutes, agenda, roster, future meeting dates, meeting PowerPoint presentations and reports is located here. Additionally, the public may view the NCRA meetings (both live and on demand) via the NIH Videocast at the following website: <http://videocast.nih.gov/>.